

INVOLVING PEOPLE IN DNA RESEARCH



A learning resource created by Jack Nunn



SCIENCE FOR ALL



LUDWIG
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GESELLSCHAFT

About this document

This document was created by Jack Nunn for Science for All on 24th September 2020, to accompany a presentation given for The Ludwig Boltzmann Gesellschaft (LBG). This document is intended to provide additional information and resources relevant to the presentation ‘Involving People In DNA Research’. This document is licensed under Creative Commons Attribution-NonCommercial 4.0 International (CC BY-NC 4.0). Contact Jack.Nunn@ScienceForAll.World and learn more at ScienceForAll.World.

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Aims

The aim of the presentation and this accompanying resource is to explore the concept of participatory action research with real examples, and to explain ways of planning, reporting and evaluating the process.

Outcomes

After attending the presentation, participants will be able to:

- Explain the concept of participatory action research
- Explain the importance of evidence-informed methods of participatory action research
- Summarise how participatory action research has been used in DNA research
- Explain how participatory action research can be planned, reported and evaluated using for Standardised Data on Initiatives (STARDIT)
- Summarise how anyone can get involved in co-developing STARDIT

About the speaker - Jack Nunn

Jack Nunn's research area is in creating and evaluating equitable and ethical ways for people to get involved in all aspects of research and science, including public health and environmental research.

- **Jack is the founder and Director of the charity 'Science for All'**, working to involve people in doing research by building partnerships between the public and researchers (ScienceforAll.world). This work includes creating standardised ways of reporting data about initiatives (STARDIT)¹.
- **Jack is a PhD researcher in the department of Public Health at La Trobe University** (Australia), where he is currently exploring genomic research and how people can be involved in shaping the future of this research².
- Jack has worked for over ten years to involve patients and the public in health and social care research. Projects have included '**Building Research Partnerships**' which is a free course to train the public and researchers in how to work together at every stage of the research cycle³⁴.
- He has recently worked on projects with Cochrane Australia⁵, the World Health Organisation, the Australian Department of Health, the Poche Centre for Indigenous Health and the UK's National Institute of Health Research.
- Jack is a member of the Australian Federal Departments of Health's Medical Services Advisory Committee Evaluation Sub-committee, on the editorial board for 'Research Involvement and Engagement', the 'WikiJournal of Science' and the 'WikiJournal of Humanities'. He is the Strategy Liaison for the WikiJournals and a member of the Cochrane Advocacy Advisory Group.

About Science for All

'Science for All' is a charity that supports everyone in the world to get involved in shaping the future of human knowledge.

We enable people to share knowledge and ideas, use the scientific method to create new knowledge and support more people to get involved in shaping the future of human knowledge.

What we do

We recognise that many of the challenges facing the planet today do not have solutions which fall into categories such as 'public health', 'environmental studies' and 'education'. We recognise that knowledge takes many forms - this includes people who are subject area experts, people with traditional, indigenous or local knowledge – and those with big dreams and big ideas.

Our aim is to bring together experts from these diverse areas to work in partnership with as many people as possible by using a combination of free face-to-face events in metropolitan and rural areas, as well as online tools.

Learn more

[Here is a short video](#) summarising the work of the charity and why it exists.

Learn more at: [ScienceForAll.World](#)

Introduction

Defining participatory research

- Today we're working in English and using the words 'participatory action research' – which is defined on WikiData as 'an approach to research where research is carried out "with" people rather than "on" them'⁶. That definition is adapted from INVOLVE⁷.
- If we were working in German, we might say 'partizipative aktionsforschung'⁸. There's no German translation of this concept on WikiData, yet.
- I am always very aware of the importance of attempting to work across languages and cultures – collectively agreeing definitions - this will be a theme throughout this presentation.
- The Wikipedia entry for participatory action research says the concept 'resists definition'⁹ – so how are we supposed to agree when we're doing it, let alone what the best methods are for doing it?
- Participatory research is an umbrella term which describes a number of related approaches, including ^{10(p1)}:
 - community-based participatory research
 - participatory action research (including critical participatory action research)
 - participatory health research
 - community-partnered participatory research
 - cooperative inquiry
 - other forms of action research embracing a participatory philosophy which may include 'co-design' of research and other kinds of research which might include forms of 'public involvement' (or sometimes 'engagement').
- The term 'participatory research' will be used to refer to all variations of this method, unless explicitly stated.
- At the core of participatory research is critical reflexivity, a process which asks people involved to reflect on the causes of problems, any solutions and the actions that people can take to improve the current situation ^{11(p11)}. It is a form of collective self-reflective enquiry undertaken by participants in order to understand their situation from a number of perspectives^{12(p153)}.
- In a health context, participatory research attempts to reduce health inequalities by supporting people to be involved in data collection, reflection and ultimately actions to improve their own health ¹³. It is an interactive process, seeking to understand and improve things through change ¹³.
- Participatory research integrates knowledge translation into the research process, by involving those who can inform future actions as partners in the research.

Definitions from Wikipedia

These definitions are from the [English Wikipedia entry on participatory action research](#):

- It is an approach to research in communities that emphasises participation and action.
- It seeks to understand the world by trying to change it, collaboratively and following reflection.
- Emphasizes collective inquiry and experimentation grounded in experience and social history.

- "communities of inquiry and action evolve and address questions and issues that are significant for those who participate as co-researchers"

Origins and parallels of participatory research

At the core of participatory research is Paulo Friere's concept that reflection about the world requires action in order to transform it.

"to see the world not as a static reality, but as a reality in process, in transformation" ^{14(p12)}

This perspective requires viewing the world as something changing and changeable. This was articulated in a 1993 World Health Organisation report which articulates alternative futures, dividing them into possible, plausible, probable and preferable ^{15(p5)}. Participatory research offers an opportunity for people in certain situations or affected by certain health inequalities to take part in shaping this future – collectively attempting to articulate and then achieve what is preferable.

The origins of participatory action research have roots in methodological critiques of conventional research which did not acknowledge power structures inherent in research, in particular, the position of relative power of the researcher in comparison to the research participant ^{16(p136)}.

Involving people in health and environmental research recognises that some improvements can only be achieved by actively involving people ^{17(p4)}. Effective public health requires a range of methods beyond epidemiological methods in order to reflect the diversity of the issues it is trying to solve ^{18(p174)}. The question of which or whose values should direct decisions in health and research, while complex, can be navigated by participatory methods, as long as they are transparent, accountable and with clear boundaries for decision making agreed in advance.

Participatory approaches in research share a number of significant connections to existing qualitative methodologies and methods yet the constructivism at the core of participatory research ensures that this research method reflects that there is no 'one truth' or objective answer, but that there are multiple ways to ask a question and try to improve health inequalities ^{19(p2)}.

Evidence-informed participatory research?

At the moment, there's no standardised way to describe how people have been involved, or to report the impacts of involving people. In a 2019 scoping review about public involvement in genomics research, we concluded²⁰:

"The limited number of initiatives reporting public involvement and its impact in this study suggests there would be significant value in developing a more systematic method of both reporting and evaluating how people are involved in human genomics research. Data from such reporting could provide the evidence required to inform future policy around involvement of the public, as human genomics research continues to grow".

This issues and ways of overcoming it are what will be explored for the rest of this resource.

Standardised Data on Initiatives (STARDIT)

STARDIT stands for Standardised Data on Initiatives, a working platform for a standardised way to describe the who, how, what and any impacts of initiatives such as research, policy, educational interventions, international development programs and more¹.

Too often, information about initiatives and their impacts is not consistently reported across disciplines, or even across departments. STARDIT is being co-designed by people from multiple disciplines and organisations around the world, to create a standardised way to share information about initiatives.

STARDIT creates a standardised way to share information about which tasks were done, who completed the tasks, which people or organisations were involved and any impacts made. It also offers a way to add updates throughout the lifetime of an initiative, from planning to evaluation. STARDIT can be used across sectors including health, environment, education, manufacturing, food production and international development.

It is built in WikiData – which will help ensure data can be shared easily, with reports translated into multiple languages.

You can learn more about STARDIT at: ScienceForAll.World/STARDIT



We need to know the '**who**', '**how**', '**what**' and '**why**' of initiatives such as **research**, **education**, **policy** and international **development**.

STARDIT is designed to be useful across **all disciplines**, including health, environment, basic science, policy, education and international development.

It will share **open access data**, **reporting impacts** across **multiple human languages**.



STARDIT can report:

- Who is involved in which tasks?
- Who is funding what?
- Why do this?
- What are the outcomes?
- How will data be shared?

Get involved in helping
develop **Standardised Data**
on **Initiatives (STARDIT)**

This project supported by:



Research projects which have informed this presentation

Genomics research and involving people

Jack Nunn¹, Dr Kylie Gwynne², Dr Marilyn Crawshaw³, Dr Paul Lacaze⁴

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Involvement in research is when **researchers share power** with patients, research participants or the public so they **actively contribute to research**

1. Our review of involvement in 96 Global Alliance for Genomics & Health affiliated initiatives found people involved at all stages of research

A third of initiatives **reported involving people**, with variation in quality of reporting¹



Involvement **improves public trust**² ensuring research reflects **diverse priorities of populations**³

2. Learning was applied to four genomics research projects in Australia



We co-designed genomics research & online discussion forums



a) Australia's largest trial



Planning multi-generational study

b) Half-siblings who share the same donor father, from an **international group** of 20+



c) Aboriginal personalised medicine project⁴



d) People affected by a **rare disease**, working with charity ausEE



3. Standardised reporting of involvement in research



Reporting and analysis of involvement was standardised



- Who was involved in which tasks?
- Who is funding it and why?
- What is the outcome or output?
- How will data be shared? Is it FAIR⁵?

STARDIT is used by the **Wikimedia Foundation's** open-access journals
The **ongoing co-design process** is being hosted by 'Science for All'



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Adapted from 'Involving people in genomics research'²¹.

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Campfires and Science and ‘Wild DNA’

The ‘Wild DNA’ project involved training citizen scientists to use environmental DNA to identify critically endangered species²².



Learnings from doing participatory research

Who is involving who?

Words like ‘participation’ and ‘involvement’ can mean different things and can imply very different power relationships.

While it is important to ask ‘who is involving who’, a more helpful question can be ‘who is working with who, and how?’.

Defining the community involved in participatory research can be difficult. Using a definition whereby anyone who is not a professional researcher is a member of the community can blur lines which are already ill-defined^{19(p6)}.

Other traditional labels can be unhelpful in the participatory model as the labels project power structures onto people. For example, ‘service user’ may include anyone affected directly or indirectly by a service, ‘consumer’ uses an economic market model to classify health and research, ‘patient’ places it within a medical model and ‘survivor’ provides a more psychiatric perspective of those ‘affected’^{19(p7)}.

While co-creation of a term that people would like to use to describe themselves would be best-practice, practically a definition must be arrived at from the outset of the research. Terms such as ‘people’ or ‘the public’ are used as umbrella terms in systematic reviews and exclude fewer people than the other terms²³, but also lose some meaning in the process of generalising.

Participatory research can be carried out by various stakeholders including members of the public, health professionals and academic researchers, with all members of the group having equal influence or “equitable co-governing powers”^{11(p9),24(p8)}.

The purpose of participatory research is to help assess what needs to be done and then evaluate any actions that take place. It aims to help participants to improve understanding problems and to help elucidate any potential actions they can take^{16(p135)}. Participatory research is an appropriate method when an issue or problem is complex or may involve a number of ethical issues which require resolution. If conducted correctly, it should help participants understand their own circumstance and be able to make an informed choice about any future actions^{16(p138)}.

Examples

- **Shared Ancestry** - In the study working with people from a shared ancestry group – we involved people in co-defining their own labels, to agree how they would like to refer to themselves and other people involved²¹.
- **In a project where the aim was to improve** Precision Medicine for Aboriginal Australians, we co-designed a study protocol, which outlined how we planned to work in partnership with the local community. We co-designed how we were going to involve people in the study at every stage²⁵.
- In ASPREE project we involved members of the research team who carried out assessments, they had different insights into the study design than ‘senior’ research staff and participants, which added greatly to the value of involving them²⁶.

Motivation and values

- ‘First, check your ego and your motives. Why are you doing this? Second, you don’t need to be an expert to understand the knowledge processes of people from other cultures and enter into dialogues with them. More importantly, making your self an expert in another culture is not always appreciated by members of that culture. Understanding your own culture and the way it interacts with others, particularly the power dynamics of it, is far more appreciated’ From ‘*Sand Talk: How Indigenous Thinking Can Save the World*’, by Tyson Yunkaporta²⁷
- How are your personal values and beliefs mapped and shared? Are there any motives that might be overt or hidden?
- Does this mapping also need to be done by any organisations involved? Do other stakeholders need to be part of this mapping?

Valuing people

- How are people being valued? How is their time or expertise valued?
- Are some people involved paid and others not? Is it clear how these decisions are made?

Examples

- Wild DNA:
 - Science for All made it explicit that the purpose of the project was to increase public understanding about endangered species and improve evidence informed decision making. All knowledge would be shared open access and under Creative Commons.
 - We made it clear where money was coming from (grants and public donations), what our hourly rate was, what the decision process was for paying people.
 - People were more willing to get involved when the purpose of the research project was clear, and more willing to give their time as it wasn’t ‘for’ any one person or organisation, but for everyone²².

Boundaries

Making sure that boundaries are co-created is important. The additional resource '[Planning and reporting the co-design cycle using STARDIT](#)' provides some tools for helping do this.

Agreeing the following can help ensure everyone knows who is doing what, feels safe and is supported.

- Who is doing which tasks?
- Why? (are certain skills, knowledge or values required?)
- What isn’t being done? (define what is ‘out of scope’)
- What support is there? What isn’t supported? (is there money to pay for people’s time, is there practical or emotional support?)
- How much time? (what are the time scales, what is the expected commitment?)

For more information on this, see '[The 6Rs](#)' in the additional resources.

If you can be clear on all these, you create the enabling conditions for self-supporting communities to emerge, and it will help people make informed decisions about whether to get involved.

Communication

There's no magic tool or trick to communication. It's hard work, trial and error.

But, follow above boundaries and it will be safe and inclusive and supportive and everything else will follow.

Having open and safe online spaces is very important, and also creating spaces for support and confidential discussion is also important. Sometimes those who are leading projects need to support each other and need a space to share thoughts, concerns and ideas in a confidential space.

Example

We set up online discussion tools for planning the research and deciding ideas.

After discussions around the campfire, we planned a method online to try to catch mosquitoes. We went out and did it – and learned it's easier to be bitten by mosquitoes than to trap them. While the method has potential, we learned also involving people in collectively deciding to try a method, evaluate it and then try others works well.

Making the online spaces so that anyone can join and discuss also meant people from many disciplines could get involved.

As well as online spaces we also created safe lab spaces, working in partnership with community organisations and community lab spaces.

Transparent power structures

Who is accountable? Who isn't

If there is power in decision making, label it. It saves time and is accountable. If it's opaque, it can't be challenged.

Distributing decision making can work, however often only certain people can be accountable. For example, volunteers might come and go, but people named on grants and ethics applications are responsible for keeping things on track

If you're starting a new project, try to involve everyone in trying to label power structures, stakeholders and other people who might need to be involved.

Who decides who decides what is ethical? This is an enormously important question of power.

Initial questions in the group discussion of the communities of interest needs to involve an acknowledgement of power structures and an attempt to map who currently has the power, why – and how people feel about that and how it might impact on research.

Using tasks, not 'roles' to describe what needs to be done can help keep things focussed.

Example

Many people involved with Science for All have said that the transparent values and power structures of the charity have made them want to be involved.

Having transparent values are very important, many people have reported getting involved as the values align with their own.

Volunteers and experts from universities volunteering their time and skills helped the projects progress in new ways, helping achieve world-firsts in the project, but a core team who are accountable and supportive was extremely important.

Knowing who is accountable for safety in a community lab space is very important!

Applying the participatory action research method

There are lots of ways of applying the values, principles and philosophy of participatory action research, and the main point is that the methods must be co-created with the people you are working with.

Importance of safe online spaces is important. More so than ever in the time of pandemic.

Example

With the ASPREE study, people preferred not to use social media companies.

Science for All uses Loomio on our servers as it's flexible.

Learning from Science For All projects informed how projects were set up and in turn informed how the charity ran collaborative research projects.

Learning from this is relevant to the work with vulnerable communities, including the siblings and other vulnerable groups could actually achieve this.

To be able to report on the methods in a standard way is crucial to help evaluate how things went, and help to inform future participatory methods.

The Idea Vortex - Participatory methods simplified

The stages of the idea vortex²⁸.

1. Invite people to share problems, needs or wants
2. Invite people to analyse the problem or need – ask
 - What is the root cause (where does this problem or need sit in a causal chain – does it cause other problems or needs?)
 - Ask which level it is most helpful or realistic to look at (for example, crops failing because of drought, a group may chose to look at local irrigation rather than climate patterns). Once a level of focus (causal factors) has been identified then-
 - Invite people to consider do they feel they should support or inhibit the causal factor(s)?
3. Invite people to try and group or organise any factors into a causal chain or groups (action/reaction) with an emphasis on imagining outcomes if certain factors were changed.
4. Invite people to offer solutions or share ideas about how to support or inhibit certain causal factors – ask ‘what can be done’ (at this stage it is crucial that ideas are accepted and not immediately thrown out or appraised by SMART criteria etc)
5. Ask people to look at all the solutions or ideas offered and see immediately if they could help with any of these solutions (time/expertise/skills) or know anyone who could help.

6. Ask if anyone is prepared to commit to any actions – even if that action is ‘write an action plan’.

Standardised preference mapping, reporting and evaluation

What is Standardised Data on Initiatives?

STARDIT stands for Standardised Data on Initiatives, a working platform for a standardised way to describe the who, how, what and any impacts of initiatives such as research, policy, educational interventions, international development programs and more. This article outlines how STARDIT works, and how development might continue across countries, disciplines and by multiple organisations.

Too often, information about initiatives and their impacts is not consistently reported across disciplines, or even across departments. STARDIT is being co-designed by people from multiple disciplines and organisations around the world, to create a standardised way to share information about initiatives.

By standardising how data is reported, comparisons of the effectiveness of different methods can be made. For example, comparing education initiatives for the most measurable impact on public health.

STARDIT creates a standardised way to share information about which tasks were done, who completed the tasks, which people or organisations were involved and any impacts made. It also offers a way to add updates throughout the lifetime of an initiative, from planning to evaluation. STARDIT can be used across sectors including health, environment, education, manufacturing, food production and international development.

STARDIT reports will be available open access in the public domain, with options for peer-review and verification of authorship. The data is presented in a way that is accessible to anyone. Data is in STARDIT reports structured to allow for translation into multiple languages, and increase reach across countries and communities.

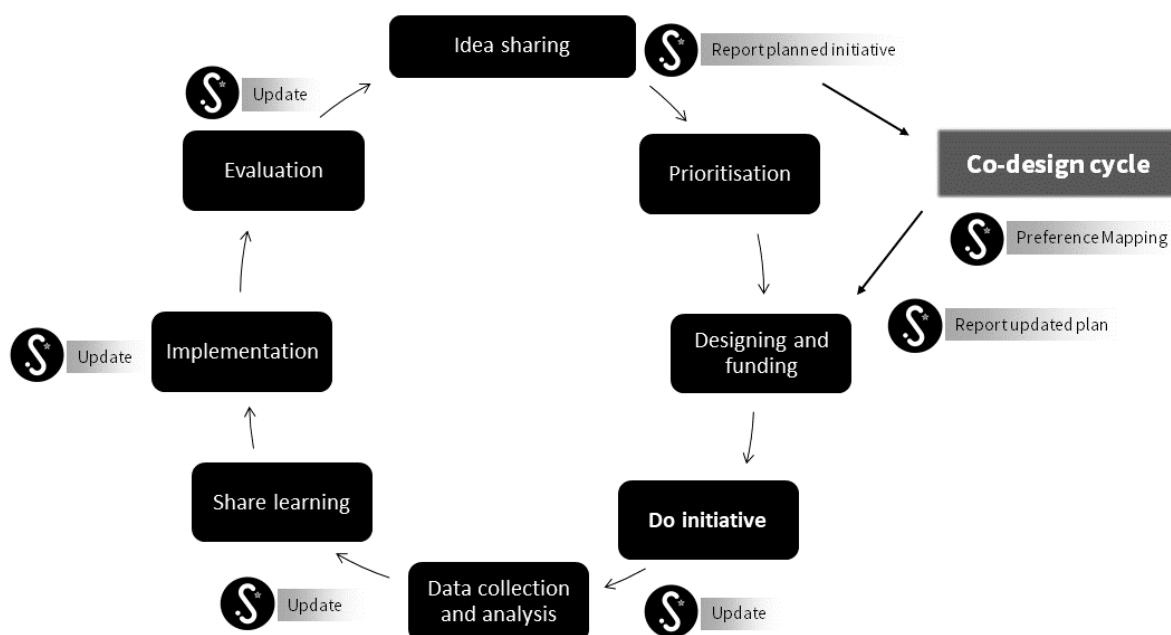
All information about the project is available free of charge under a Creative Commons licence. The project is currently hosted by the WikiJournals on Wikimedia Foundation servers. The co-creation process is being supported pro-bono by the charity ‘Science for All’ and has received in kind support from the EPPI-Centre. STARDIT is a truly collaborative project and in the Beta phase of development; the co-creators invite anyone in the world to get involved.

Additional material

Using STARDIT during initiatives

Across disciplines there are distinct stages of any initiative, including ‘plan’, ‘do’ and ‘evaluate’. The importance of involving people in initiatives is clear and there are many ways to involve people at each stage, but evidence-informed methods of doing so are lacking^{23,29,30}. This section describes how STARDIT can be used to both plan and report an initiative (Figure 1: Planning and reporting initiatives using STARDIT’), including mapping people’s preferences, co-designing how people will be involved and reporting the whole process (Figure 2 ‘Planning and reporting the co-design cycle using STARDIT’).

Figure 1: Planning and reporting initiatives using STARDIT



Planning and reporting co-design using STARDIT

How to answer questions such as ‘who decides how people are involved?’ and ‘who is involving who?’ can be difficult and is an active area of research. For example, planning a healthcare initiative requires input from both experts and also the people the initiative is trying to help. A suggested model for co-designing and reporting how people will be involved in initiatives is summarised in Figure 2 ‘Planning and reporting the co-design cycle using STARDIT’ and ‘Table 1: Summary of planning and reporting co-design using STARDIT’.

Figure 2: Planning and reporting the co-design cycle using STARDIT

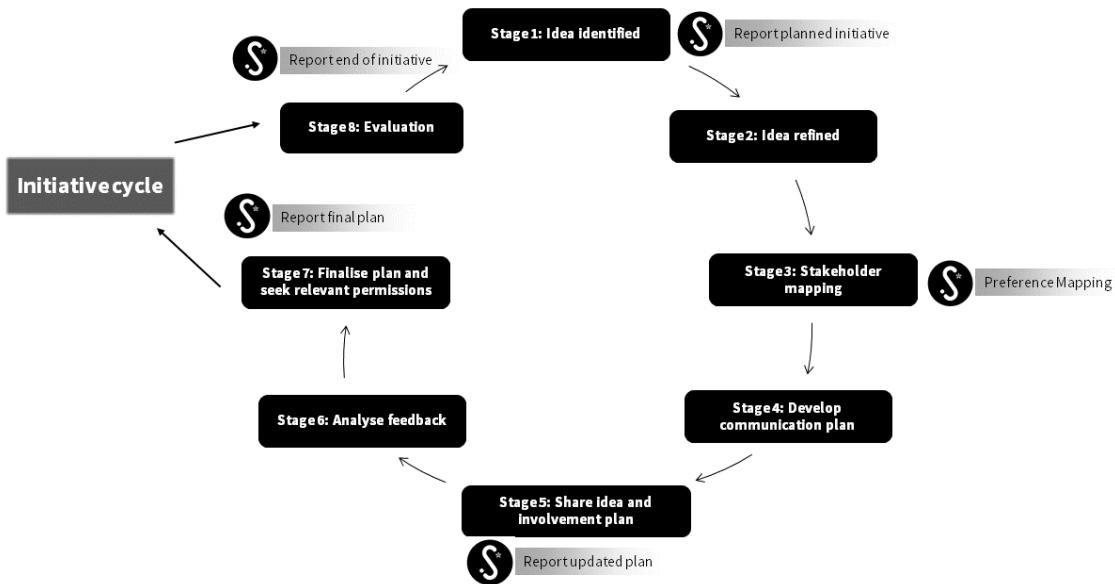


Table 1: Summary of planning and reporting co-design using STARDIT

Stage 1: Idea identified: An idea for an intervention, project or research is identified and articulated	Report planned initiative
Stage 2: Idea refined The idea is refined with a small group of stakeholders ^{19,23,31–36}	
Stage 3: Stakeholder mapping: Existing stakeholders attempt to map who is included and who might currently be excluded from the process ^{19,37}	Preference Mapping
Stage 4: Co-create communication plan Develop a communication plan to invite people to co-create involvement ^{19,31,38}	
Stage 5: Share plan: Share the idea (according to the communication plan) and ask for feedback on it (including the involvement plan) ^{36,39,40}	Report updated plan
Stage 6: Analyse feedback: Collect and analyse feedback, share results. ^{38(p1)}	
Stage 7: Finalise idea and involvement plan: Co-create the plan (including the plan for involving people) and seek relevant permissions (ethics) ^{41&2}	Report final plan
Do initiative (see ‘Planning and reporting initiatives using STARDIT’)	
Stage 8: Evaluate involvement: Evaluate the process and the impact of both the initiative and involving people in the initiative	Report end of initiative

Self-assessment: What are you doing to involve people?

How are the public involved in your work? This is an action-based approach to the spectrum of involvement, designed to aid discussion about **assessing current involvement and planning for future activities**. The pyramid gives an indication of how many people might be involved in each action.

Actions	Involve people by...
Innovating This includes prototyping, piloting, establishing and creating new ways of doing things. This can include anything from building partnerships or buildings.	Supporting them to: <ul style="list-style-type: none">• Design and carry out research• Create solutions• Implement ideas• Learn from actions
Managing, delivering and evaluating Working in partnership to manage ongoing activities.	Having: <ul style="list-style-type: none">• Clear roles and tasks for the public• Elections and interviews when appropriate• Clear and accessible accountabilities for all roles (including staff), groups and committees. Asking them to take actions such as: <ul style="list-style-type: none">• Managing or overseeing actions, processes and procurement• Directly delivering services or reviewing providers• Evaluating actions, processes and outcomes
Prioritising and planning Working in partnership to prioritise actions and plan implementation.	<ul style="list-style-type: none">• Agreeing priorities in a clear, transparent way (this can include stopping certain actions)• Having clear accountabilities for planning at all stages• Having a transparent and adaptable budget
Listening, responding and acting Actively seeking feedback, responding to ideas, compliments and complaints with actions.	Asking them to help: <ul style="list-style-type: none">• Interpret feedback• Influence responses to ideas, compliments and complaints• Asking for ideas for actions This includes telling people what this action was, particularly those who have given feedback.
Asking and discussing Asking people what they think, need and want and discussing it with them.	Inviting people from your intended audience or people you are trying to help to: <ul style="list-style-type: none">• Design how you will collect feedback and interpret the results• Identify any potential barriers that might stop people from giving feedback.
Telling Giving information about what you have done, are doing or are going to do.	<ul style="list-style-type: none">• Sharing opportunities to be involved• Asking people for ideas and support to share and disseminate what you want to tell people• Ask for feedback about how you are sharing information and attempt to measure the impact.

The 6Rs

When working with others in a group as part of a participatory research project, it can be helpful to make sure the following are as clear as possible:

Remit

- What is the purpose of the meeting/group?
- Are there any terms of reference? Does everyone have a copy?
- When they were last revised? Are they updated regularly?

Role

- Is each member clear about why they are there?
- What are people's expectations of you?
- Do you or others ever find that you have conflicting roles?
- What do others expect of you?

Representative

- Are you seen as a representative?
- If so, who are you supposed to represent? Do you have a constituency, a group of people whose views you aim to represent?
- How are you supported to be a representative? How might you gather people's views? How do you report back to them?
- Are you there because of a personal experience?

Responsibility

- What responsibilities do you or others have? (see terms of reference)
- Who sets the agenda? Is this responsibility shared?
- How are decisions made? How are they implemented? Who takes responsibility for reporting back and ensuring the wishes of the group are carried out?

Relationships

- Does it feel like being part of a team, everyone working together?
- Is there a sense of common purpose and goals?
- Do you get along with each other? Do you know each other as individuals or are you strangers brought together by your roles?

Readiness

- Are you ready to get involved? Have you considered your emotional readiness and any time commitments?
- Have you received any training to help you prepare for your role? Have you thought about how can you maintain and support your wellbeing?
- Do you know who or where you can go to for support regarding any of these issues?

Adapted from a resource in 'Building Research Partnerships' by Jack Nunn, and available under the same licence^{4,43}

Assumptions about participation and public involvement

There are many things to think about when involving the public and patients in improving services – this document is intended to help ask the right questions for the right roles.

How to use this resource: Under ‘Assumptions and barriers’, read the questions and consider if these might be barriers to involving some people, and consider how you might overcome these. ‘Learning needs and support’ examines the role in more detail and asks questions about the support people might need support to develop.

Be clear what you want– do you want ‘patient’, ‘user’ or ‘carer’ involvement, a lay perspective or just anyone who can give their time? Consider who you might unintentionally exclude by using these terms and be clear what you mean by *engagement* or *involvement*.

Assumptions and barriers	Role Description	Learning needs & support
<ul style="list-style-type: none"> • What commitment do you expect (time/financial implications) • Have you asked people to think about their emotional readiness? • Do you expect them to be reading and writing information and documents? Have you considered what formats might be appropriate? • Are you assuming a good ability to speak and read English? • Do you expect a certain educational background? 	<p>Community or lay Leader: A person who speaks and acts on behalf of all members of the public, including patients and carers and who takes a leading role in representing other lay representatives. The role may involve holding people or organisations to account.</p> <p>Community or lay representative: a member of the public (not a professional) who is a representative. They must speak and act on behalf of others. They may be guided by lay leaders but will be expected to take direct action to ensure that they are informed and able to represent the views of others.</p>	<p>How are they supported to be a representative?</p> <ul style="list-style-type: none"> • How will they be gathering views? • Will this involve research? • Do they have a budget? • Should they be paid? • Is there admin and practical support (from an organisation?) • Is there any training available? <p>Who is already doing this?</p> <ul style="list-style-type: none"> • Are there any opportunities for them to be involved in peer support or have or be a buddy? • What can be shared with other organisations? (E.g. learning, resources) <p>How are people involved?</p> <ul style="list-style-type: none"> • Can people be involved in other ways? (e.g. is it face to face meetings? What can be done online, what cannot?)
<ul style="list-style-type: none"> • Are the people who have engaged with you the only people who might be interested? 	<p>Interested and engaged members of the public: People who know about and/or are interested in decisions being made, but may take no direct action other than giving feedback, being involved in a public dialogue or signing petitions.</p>	<p>Could there be a need for translation?</p> <ul style="list-style-type: none"> • Are there any groups or organisations who could support with this? <p>Remember: ‘public dialogue’ is not fully ‘representative’ but can give a strong indication of how the public at large feels</p>
<ul style="list-style-type: none"> • It is easy to assume that people who are not engaged don’t want to be. • Often they won’t even know how they can contribute or be involved • Some may not be able to afford the time, caring responsibilities or travel. 	<p>Uninformed, disengaged or disinterested members of the public: people who, for whatever reason, are not engaged, informed or interested in influencing decision making or shaping the future of health and social services.</p>	<p>A majority of the population are in this category.</p> <ul style="list-style-type: none"> • What information or support might some people need to help engage them or move them into other roles? • What might make people move back into this role? (e.g. not seeing direct improvements, or too much of organisational change?)

Remember: roles are not always fixed, they are often just a way of articulating different things people can or should do. Tasks can be more focused. There is always a way for dedicated people to give their time and develop their skills, whatever the label or role description

Considerations at different stages

Below are some things to consider at different stages of participatory research.

Ethics

Who decides who decides what is ethical? Answering this question is a complex and important part of the participatory research process.

Researchers must also be cautious of raising expectations at the start of the research process that might not be realistic. For example, making it explicit whether the process will examine the current context and potential actions, or actually carry out an action and evaluate it ^{16(p143)}.

An exploration of attitudes about confidentiality and data sharing must also take place at the start of the research to ensure that incorrect assumptions have not been made. For example, it may be incorrect to assume participants wish to remain anonymous, as they may wish to be co-authors. Different participants might have different preferences about how data will be shared, so these must be balanced with the research design and agreed in advance ^{16(p144)}.

Design

Participatory action research requires action – something which is changed and then evaluated collectively ^{12(p153),16(p136)}. It is best-practice to include participatory research elements in the research design ^{19(p2)}. A review of participatory research suggests the method can improve how culturally appropriate the research is to the group involved and also ensures the method is logically realistic ^{24(p8)}.

With participatory research there are two kinds of reflection that are relevant when designing research. Firstly is personal reflection, which examines personal assumptions, values and experiences. Secondly is epistemological reflection which requires a recognition of the limits of research methods, and ultimately, science itself ^{19(p14)}. The method attempts to remove distinctions between the research and participants, creating an inquiry process which aspires towards egalitarianism ^{44(p242)}.

During

During the research process, everyone involved in the research must reflect on the following and how this may enable or hinder the research process ^{19(p16)}:

- personal values or experiences and potential difficult or negative reactions (for example, might some things ‘trigger’ difficult emotions)
- Relationships within the group, community or with other stakeholders
- The potential and the limits of the research process itself within the wider context of the political, social and economic conditions.

For people involved in participatory health research who are not health professionals, the process also involves ‘critical health literacy’. This is distinct from functional or interactive health literacy as it describes how people can act together with others to improve any factors which affect the health of the group as a whole ^{11(p12)}.

As a result, initial questions in the group discussion of the communities of interest needs to involve an acknowledgement of power structures and an attempt to map who currently has the power, why – and how people feel about that and how it might impact on research.

Facilitation

Facilitation is a vital role in the participatory research process. Facilitation can require people to have the task of being an intermediary or an egalitarian. Their task is to attempt to promote equal dialogue, while aspiring to achieve specific goals or outcomes. It is a process that requires self-critical reflection. It can take place both face to face and using online tools.

Involving impartial or neutral facilitators for some discussions may reduce undue influence on discussions, as leadership requires facilitating shared-decision making at every stage of the research.

Facilitation needs to create the enabling conditions for good communication, including respecting everyone's individual dignity and privacy. This ensures that people feel they can trust the people involved and the process ^{19(p6)}.

The non-professional researchers involved in participatory research may perceive the research and the process differently as the research progresses. Anxiety or distrust may change transform to self-confidence and a feeling of belonging if the enabling conditions are created ^{19(p13)}.

Results – no consensus required

Participatory research does not require consensus, it is the process of uncovering and examining different perspectives. The concept of productive conflicts followed by useful negotiation is helpful, as it assumes there will not be homogenous perspectives yet also presumes the process for managing conflict will be sufficiently robust to result in useful negotiated outcomes ^{24(p2)}.

Academic researchers involved should bring their knowledge to the discussions, however, they should attempt 'critical reflection', in particular if they are in a facilitation role ^{11(p16)}.

Knowledge is created in the communicative spaces, created and facilitated by the research process. If the process is sound, it will engender trust through encouraging shared behaviours which are aligned with the universal human values of dignity and respect ^{11(p16)}.

This process also allows an exploration of what is known, what we know is unknown, agnotological exploration (a study of culturally induced ignorance) and an agnoiological exploration (that of which we will always be ignorant). By exploring the limits of both the positivist method and our own knowledge, this mapping can produce a helpful framework within which to focus discussion and action.

With everyone in the role of 'co-researcher' collective learning transforms into a process whereby people can act based on research findings and have an impact beyond a traditional definition of the scientific community ^{11(p17)}. In this sense 'co-researchers' can then move from a stage of co-designing to co-implementing solutions ⁴⁵.

Sharing findings

The process of articulating and sharing findings should be participatory, with issues such as authorship discussed transparently at the start of the research ^{16(p144)}.

Impact

Measuring and reporting impact is challenging as outcomes can be long term and short term, and involvement can vary from person to person ^{11(p17)}.

A review of the benefits of participatory research suggested that participatory action research can ^{24(p2)}:

- ensure culturally and logically appropriate research

- enhance recruitment capacity
- generate professional capacity and competence in stakeholder groups
- (result in productive conflicts followed by useful negotiation
- increase the quality of outputs and outcomes over time
- increase the sustainability of project goals beyond funded time frames and during gaps in external funding
- create system changes and new unanticipated projects and activities

The negative examples identified by the review illustrated why these outcomes were not a guaranteed product of participatory action research, but rather were contingent on key aspects of context.

Standardised Data on Initiatives (STARDIT) is a way to plan, report and evaluate participatory research, including any impacts from involving people and any impacts from the research itself⁴⁶.

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